

# DEVELOPMENTAL DISABILITIES PRIMARY CARE PROGRAM

Improving health and health care  
experiences for adults with IDD

OASIS Conference, May 07, 2021





# Nice to Meet you



---

**Heidi Diepstra, PhD, MA**  
Senior Research Associate &  
Knowledge Translation Lead

# Agenda

1. Who we are
2. History
3. Pre-pandemic: identifying the gaps
4. COVID-19 response: seeing the gaps
5. Forward together: addressing the gaps
6. Questions

# A Canadian Network



# Who we are

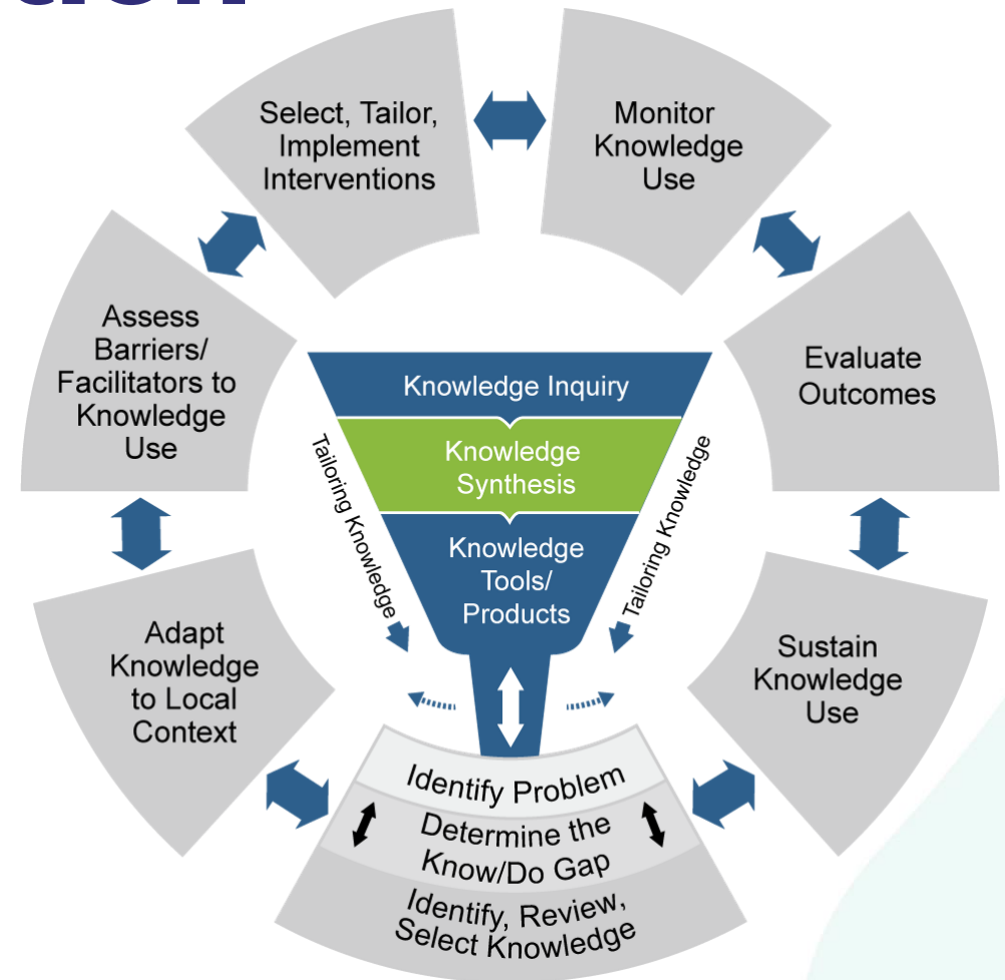
## Vision and mission

- ▶ Adults with intellectual and developmental disabilities have a right to primary care that meets their specific health and developmental needs
- ▶ Develop standards of care, resources, and partnerships to promote and improve the primary health care for adults with intellectual and developmental disabilities



# Knowledge translation

- ▶ Dynamic and iterative process that includes **synthesis**, **dissemination**, **exchange** and ethically sound **application** of knowledge
- ▶ Takes place within a complex system of interactions
- ▶ To improve health services and products, and strengthen the care system



# Knowledge translation

## Knowledge translation

- ▶ Strategies to make science findings understandable to the knowledge user

## Dissemination

- ▶ Targeted distribution of information and intervention materials to a specific audience

## Implementation

- ▶ Use of strategies that promote the adoption, integration, and scale up of evidence-based interventions and change practice within specific settings



*Failing to use available science is costly and harmful; it leads to overuse of unhelpful care, underuse of effective care, and errors in execution.*

*-Donald Berwick*

Institute for Healthcare Improvement, 2003





# History

	Knowledge synthesis	Knowledge inquiry & creation	Knowledge dissemination & implementation
2006-2008	<i>Consensus guidelines</i> <b>Primary Care Initiative</b>		MedEd Training course
2011	<i>Consensus guidelines update 1</i>	<i>Health Care Access Research &amp; Developmental Disabilities (HCARDD)</i>	<i>Primary Care Toolkit</i> CFPC DD committee
2013-2014		<i>Atlas of primary care for adults with DD</i>	Family Medicine Curriculum; E-course MH
2016 - 2019	<b>Primary Care Program</b>	<i>Making the invisible visible</i> <i>Gaps in service use</i> Implementation research	
2018	<i>Consensus guidelines update 2</i>	<i>Azrieli Adult Neurodevelopmental Centre (CAMH)</i>	<i>Primary Care E-Toolkit update</i> ; Website Education (ECHO)

# **PRE-PANDEMIC**

Identifying the gaps

# Guidelines

Empirical

Experiential

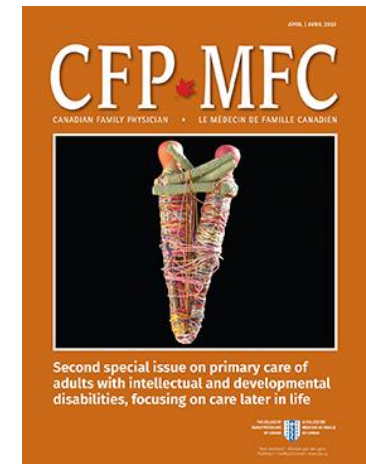
Expert

Ecosystem

## Primary care of adults with intellectual and developmental disabilities

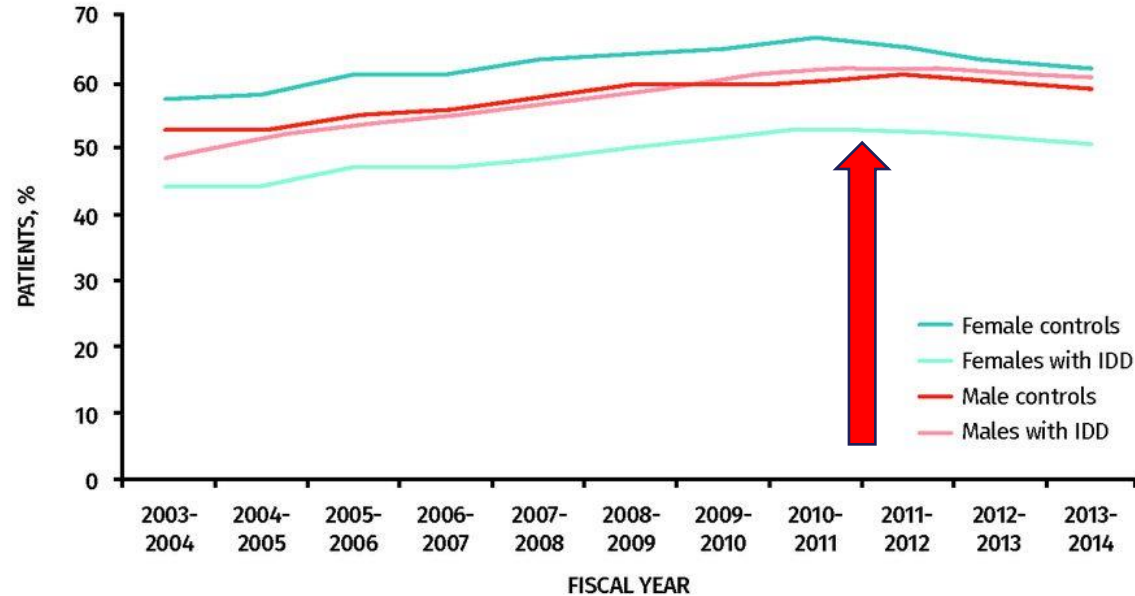
2018 Canadian consensus guidelines

William F. Sullivan MD CCFP(COE) FCFP PhD Heidi Diepstra MA PhD John Heng MA Shara Ally RN MN  
Elspeth Bradley MBBS PhD FRCPC FRCPsych Ian Casson MD MSc FCFP Brian Hennen MD MA FCFP FRCGP  
Maureen Kelly MPA Marika Korossy Karen McNeil MD CCFP FCFP Dara Abells MD CCFP MScCH  
Khush Amaria PhD CPsych Kerry Boyd MD FRCPC Meg Gemmill MD CCFP Elizabeth Grier MD CCFP  
Natalie Kennie-Kaulbach ACRP PharmD RPh Mackenzie Ketchell MS BCBA Jessica Ladouceur MD CCFP  
Amanda Lepp MD PhD Yona Lunsky PhD CPsych Shirley McMillan RN MN CDDN PhD Ullanda Niel MD CCFP  
Samantha Sacks MD CM CCFP Sarah Shea MD FRCPC Katherine Stringer MBChB CCFP FCFP  
Kyle Sue MD MHM CCFP(PC) Sandra Witherbee RN



# Underuse of effective care

**Figure 1.** The proportion of adults who received a health examination or had a Primary Care Quality Composite Score  $\geq 0.6^*$  from 2003-2004 to 2013-2014 by IDD status and sex



IDD—intellectual and developmental disabilities.

\*The Primary Care Quality Composite Score combines 7 screening maneuvers that are identified as either up-to-date or not. A score is created based on the proportion of eligible maneuvers that are up-to-date.

Glenys Smith, H el ene Ouellette-Kuntz and Michael Green  
Canadian Family Physician April 2019, 65 (Suppl 1) S53-S58;

# Overuse of health services

- ▶ Nearly 2x more likely to have at least one return visit to an emergency department within 30 days of an earlier visit or hospitalization (34.5% vs. 19.6%).
- ▶ More than 3x more likely to be readmitted to hospital within 30 days of their initial discharge (7.4% vs. 2.3%).
- ▶ 6.5x more likely to have at least one alternate level of care day in hospital (the need to remain in hospital despite being well enough for discharge; 4.6% vs. 0.7%).

(Lin et al, 2013. Addressing Gaps in the Health Care Services Used by Adults with IDD. Report)

# Errors in execution

- ▶ Adverse effects of long-term medication use (e.g., antipsychotics)
- ▶ Multiple medications and polypharmacy (> 5 medications)
- ▶ Inappropriate use and high rates of psychotropic medications for behaviours that challenge

(Lunsky Y, et al., Toronto, ON: ICES, 2013)

# Costly

- ▶ Among adults with IDD, 36% had annual health care expenditures greater than \$2610 CAD in 2009-10 (top decile of all Ontario adults under 65).
- ▶ Adults with IDD are nearly 4 times as likely to incur high annual health care costs than those without IDD.
- ▶ Greatest health care expenses are due to hospitalizations, especially psychiatric hospitalizations, continuing care/rehabilitation costs and medication costs.

(Lunsky et al. JIDR, Nov 2018)



**Knowledge  
into practice**



# Practice tools

Point-of-care tools

FAQs

Health Watch Tables

Monitoring tools

Patient-engagement tools



[ddprimarycare.surreyplace.ca](http://ddprimarycare.surreyplace.ca)

- Primary Care Tools
  - COVID-19 Tools
  - Approaches to Care & General Considerations
    - About My Health
    - Communicate CARE
    - Decision-Making: Promoting Capabilities
    - My Health Care Visit
    - Health Check**
      - Genetic Assessment
      - Frequently Asked Questions
      - Adaptive Functioning and Communication
      - Psychological Assessment
      - Health Care Transitions
    - Physical Health

# Health Check

## A Comprehensive Health Assessment of Adults with Intellectual and Developmental Disabilities

### INTRODUCTION

This point-of-care tool assists primary care providers to implement the evidence-informed Comprehensive Health Assessment or “Health Check” for adults with intellectual and developmental disabilities (IDD). It identifies health issues for adults with IDD that family physicians should consider when they undertake annual Health Checks.

Health Check forms for integration with Electronic Medical Records are in development. Contact [ddpcp@surreyplace.ca](mailto:ddpcp@surreyplace.ca) for more information. Visit [ddprimarycare.surreyplace.ca](http://ddprimarycare.surreyplace.ca) for updates.

[Download: Health Check Tool](#) [Leave us your feedback](#)

### RELATED GUIDELINES

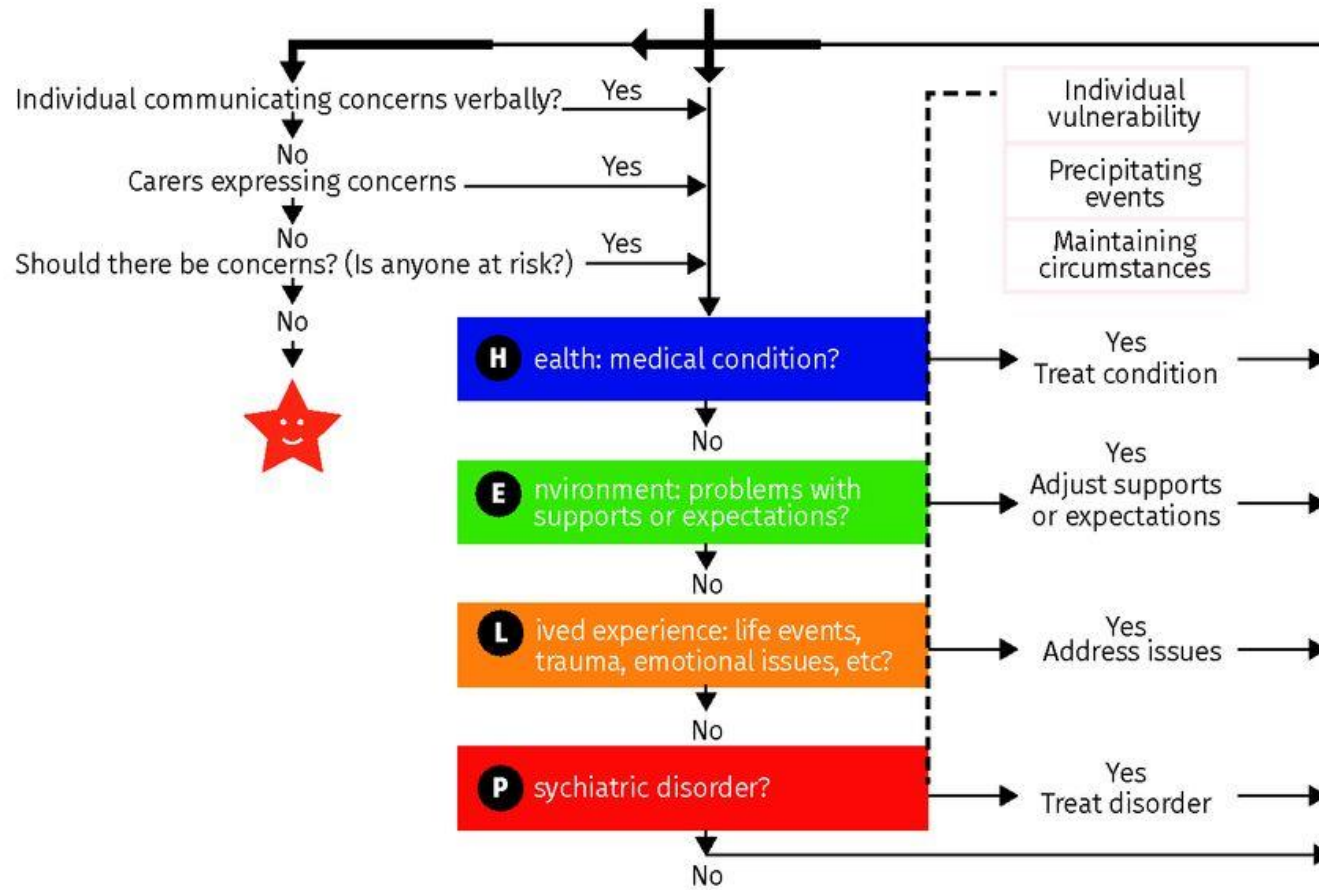
[Health Assessments](#)

### SHARE



**Figure 1. Diagnostic framework for behaviours that challenge**

Patient brought to family physician or psychiatrist because of mental distress or behavioural concerns



Reproduced from Bradley and Korossy.<sup>13</sup> Copyright Elspeth Bradley, 2016.

# **COVID-19 RESPONSE**

Seeing the gaps

CONTRIBUTORS OPINION

# Canada must put human rights at the centre of its COVID-19 response

By **Renu Mandhane** Contributor  
Thu., April 2, 2020 | 3 min. read

# People with Down syndrome have 10 times the risk of death from Covid-19 as those without, study finds

By **Shelby Lin Erdman** and **Katia Hetter**, CNN  
Updated 6:40 PM ET, Fri October 23, 2020



'Human rights protections do not go away in a pandemic,' adjudicator writes in decision

Liam Casey · The Canadian Press · Posted: Mar 25, 2021 10:54 AM ET | Last Updated: March 25

PMN Politics / PMN News / PMN Life / PMN Health / PM

Facebook Twitter

# Pandemic highlights existing barriers for those with communication disabilities

**The Canadian Press**  
Michelle McQuinn

CORONAVIRUS | News

# 'It's devastating' disabled people not prioritized in vaccine rollout, advocates say

By **Jeremiah Rodriguez** CTVNews.ca Writer  
@jrerodriguezz | Contact

Published Monday, February 8, 2021 6:22PM EST

# Covid-19 deaths must prompt better healthcare for people with learning disabilities

*Jonathan Senker*

STAR COLUMNISTS OPINION

# The forgotten sector in the COVID-19 fight

By **Bob Hepburn** Star Columnist  
Thu., April 2, 2020 | 3 min. read



## COVID-19 Hospital Transfer Form for Patients with Intellectual and Developmental Disabilities

### Tips for family members

As a family member of someone with an intellectual or developmental disability you might worry about your loved one falling ill with COVID-19 and having to go to the hospital. You might not be able to accompany them to the hospital and visitation may be restricted. The Hospital Transfer Form lets hospital staff know how to best accommodate your loved one's medical and communication needs and try to help the person cope with being in hospital.

#### When should you fill in this form?

In an emergency you will not have time to gather information. Fill in the Hospital Transfer Form together in advance of your loved one becoming sick enough to require hospitalization.

#### What information goes into this form?

Include **medical information** about diagnoses, medications and life-threatening issues like swallowing problems, allergies, especially allergies to latex or to medications used to put people to sleep. Be sure to include instructions that

Attach any additional **important documents** to the form, like a medication list, a doctor's note summarizing health history, photocopies of any legal documents about substitute decision makers (if this exists) or an advance care plan.

An **advance care plan** explains what kind of medical care your loved one does or does not want when he or she gets seriously ill with coronavirus. If you want to discuss advance care planning with your loved one, there are social stories and other materials to help you (see supporting materials).

Use your judgement and relationship with the person with an intellectual or developmental disability to determine what conversations will be helpful in helping your loved one cope emotionally with being ill and preparing for potential hospitalization.

#### What else should you do to be prepared?

**Laminate the Hospital Transfer Form** or put it in a clear plastic sleeve or zip lock bag together with any other important documentation. If the hospital will not accept paper forms,

# COVID-19 Hospital Transfer Form for Patients with Intellectual and Developmental Disabilities

Name:

First

Last

DOB:

**ALERTS (write detailed notes in the box below):**

**Medical**

- I have allergies (may include food, latex, medications including general anesthetic)
- I have swallowing difficulties
- I have a family history of complications with anesthetic

**Attachments**

- note/summary from my family doctor
- behavior plan
- advance care plan
- information about communication tools or device
- substitute decision maker documentation

**Important information about my care**

- I need someone who knows me well to be with me. I need this to be able to communicate with staff and/or to remain calm and keep everyone safe
- I have communication support needs (e.g., device, board, speech impairment, ESL, deaf/hard of hearing, blind)
- I need sedation for painful procedures (e.g., swabbing, IV, bloodwork)
- I may hurt myself when scared or confused
- I may hurt others if scared or confused
- I might try to run away if I am scared or confused
- I have a hard time staying still
- I have physical care needs (e.g., eating, mobility, bathing)

Notes:

**Health decisions are usually made**

- On my own
- With support
- By my substitute decision maker

**People who are important to me and how to reach them**



# COVID-19 Advance Care Plan: A Guide for Caregivers of Adults with Intellectual and Developmental Disabilities

## Introduction

This tool guides care providers of adults with intellectual and developmental disabilities through the process of advance care planning regarding possible medical treatments for COVID-19. Advance care planning is a process that promotes person-centred care, by the individual's present goals and values along with his or her preferences regarding future health care. For adults with IDD, this process involves the adult's substitute decision-maker (ideally the family physician), and others who know the adult well, the adult trusts, and who are willing to support this process. Adults with IDD should be supported with supports as needed, to participate as much as they can and wish to. They do not need to pass a legal capacity test to contribute to this process.

## How to use this tool

### What is an Advance Care Plan?

- ▶ An Advance Care Plan is a document that outlines the outcome of discussions in the advance care planning process.
- ▶ By completing an Advance Care Plan, the adult with IDD is *not giving consent or refusal* to future medical treatments, providing guidance directly to the authorized substitute decision-maker, and indirectly to (health)care providers.
- ▶ Refer to an Advance Care Plan *when an adult with IDD becomes incapable of contributing* to discussions or decisions about the level of care or specific treatments.

## COVID-19 Advance Care Plan: Form

Surrey Place Developmental Disabilities Primary Care Program

1. Use the COVID-19 Advance Care Plan: Guidance for discussion (Guidance A1 to C7; pages VI-VIII) to fill in this form.
2. Attach a paper copy of this plan or an electronic attachment to the patient's COVID-19 Hospital Transfer Form and to the family physician's Cumulative Patient Profile (CPP) record.
3. Give a copy of this form to the person's substitute decision-maker(s) to retain and refer to.
4. With the consent of the adult with IDD (if capable) or their substitute decision-maker, inform everyone in the person's regular circle of care about this Advance Care Plan, how to contact the substitute decision-maker(s), and specific directives in C7.

This Advance Care Plan has been completed by:			Date:
	First Name	Last Name	Relationship
<input type="checkbox"/> Adult with IDD:			
<input type="checkbox"/> Substitute decision-maker (highest ranked):			
<input type="checkbox"/> Substitute decision-maker (next highest ranked):			
<input type="checkbox"/> Family physician or other healthcare provider:			
<input type="checkbox"/> Other (family, other caregiver or people who know the adult with IDD well):			

### A - SUBSTITUTE DECISION-MAKER

Substitute Decision-Maker (SDM):			(see pages VI-VIII) A1   A2   A3
First Name:	Last Name:	Relationship:	
Phone (mobile # preferred):		E-mail:	
Address:			

Next highest ranked Substitute Decision-Maker (if the above SDM is unavailable):			A1   A2   A3
First Name	Last Name:	Relationship:	

## Getting Ready for My Shot

### Accommodation request and preparation form for people with intellectual and developmental disabilities

#### Tips for caregivers

People with developmental disabilities (e.g., Down syndrome, Autism) might be uncomfortable with injections or reject medical procedures based on previous negative experiences, fear, or limited understanding. Good preparation can help to make sure that vaccination causes minimal distress. People have unique needs. Think of strategies that might work best for the person you care for.

Prepare the attached **Getting Ready For My Shot** form together and use it when you need to inform staff at the vaccination site about any special needs or accommodations.

#### Making a decision

download at public health websites or the doctor's office.

#### Preparing while you wait

- ▶ Be prepared to answer some medical screening questions at the vaccination site. This includes information about medical history (e.g., allergies, immune or blood disorders) and medications.
- ▶ Know which documents you must bring, such as identification, consent form, or a health card. Collect all documents in one folder.
- ▶ Discuss who the person would like to bring for support and comfort.
- ▶ Think about what will motivate the person and choose a reward together. For example, think of a fun activity you will do after the vaccination.
- ▶ There will be a waiting time after the vaccination.



COVID-19 VACCINE SOCIAL STORY

[Twitter](#) [Instagram](#) [Facebook](#) @SurreyPlaceON

SURREY PLACE



CAREGIVER TOOLS

COVID-19 VACCINES:  
GETTING SET TO GO

SURREY PLACE

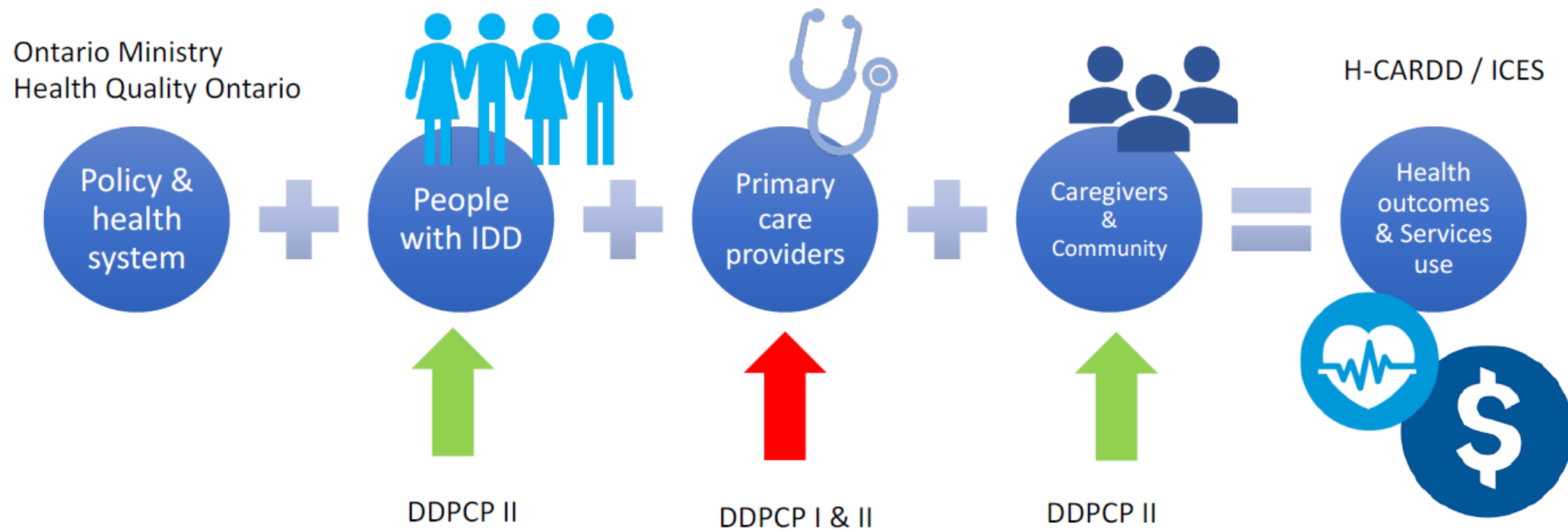
# Emerging issues

- ▶ The right to accommodation
- ▶ Virtual primary care and e-health
- ▶ The role of caregivers
- ▶ Supported healthcare decision-making
- ▶ Mental health and behaviours that challenge
- ▶ Aging and end-of life care
- ▶ Determinants of health

# **FORWARD TOGETHER..**

Addressing the gaps

# Within a (complex) system of care





# Toronto doctor challenges Commons committee to prioritize ‘social recovery’

0 Comments

Share on:



*While the pandemic’s third wave rages, we focus on the illness around us and the hardships caused by another lockdown. But the infections will clear and we will emerge from this moment into a different society, one in which social rifts have been laid bare. The recovery from the social pandemic will require more work and resources, over a longer time, than the recovery from the infectious disease pandemic. On April 23, I challenged the House of Commons Standing Committee on Health to prioritize the social recovery:*

“I have spent most of my career in primary care clinics at St. Michael’s and recently at a community health centre.”

“This infectious disease pandemic has been a doctor. I work with people including poverty and social inequality. The science shows higher rates of chronic disease and mental health issues.”

**“In COVID-19, the communities I work with have faced greater hardship than most. This infectious disease pandemic, placed on top of the longstanding social pandemic, has created what is termed a syndemic – a synergistic pandemic – in which the spark of COVID has ignited the tinderbox of social inequity built into the structures, policies and institutions of our society”.**

AUTHOR



**Gary Bloch**  
Contributor

Gary Bloch is a family physician with Unity Health Toronto, an associate professor at the University of Toronto and a senior fellow with the Wellesley Institute.

THIS ARTICLE

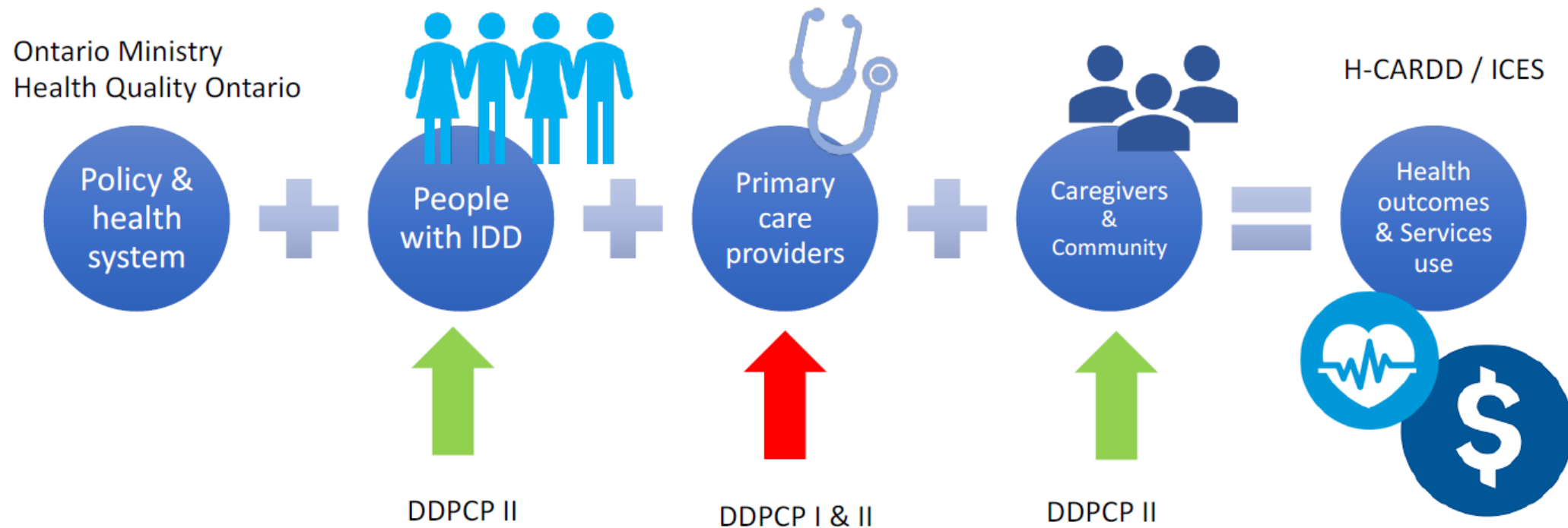


This article on your website under the

# Recommendations

- ▶ Strengthen social support programs to provide a foundation for health.
- ▶ Collect data to make social pandemics visible.
- ▶ Empower those who have been most impacted by adverse social conditions to lead these changes.

# Within a (complex) system of care





# Healthcare providers

## Barriers

- ▶ IDD specific knowledge
- ▶ Integration of tools in EMRs
- ▶ Communication
- ▶ Incentives
- ▶ Complexity
- ▶ Attitude



# Lived experience

## Barriers

- ▶ Time
- ▶ Communication
- ▶ Inclusion in decision-making
- ▶ Waiting times
- ▶ Trust and fears
- ▶ Environment



# About My Health

Surrey Place Developmental  
Disabilities Primary Care Program

## 1 My Information

<b>Name</b>		<b>Birthday</b>	<b>I like to be called</b>
First	Last	Year   Month   Day	<input type="checkbox"/> He <input type="checkbox"/> She <input type="checkbox"/> They

<b>My Address</b>		<b>My phone number</b>	
Apt #	Street	Province	Postal Code

<b>My health card number</b>	<b>Expiry date:</b>
------------------------------	---------------------

**I live (check all that apply)**

Alone   
  With family   
  With parents   
  With roommates   
  Other: \_\_\_\_\_  
 With spouse/partner   
  With friends   
  In a group home   
  In supported independent living

## 2 Things I want you to know about me (Note: think about who will be seeing the form when you decide what to include)

<b>My interests and what I like to do</b>	<b>Important people in my life</b>	<b>Difficult life experiences I have had that I want you to know about</b>

## 3 My emergency contact

<b>Name</b>	<b>Relationship to me</b>
First   Last	

# Preparing for My Health Care Visit

Surrey Place Developmental  
Disabilities Primary Care Program

## FILL OUT BEFORE GOING TO THE VISIT BY ME AND PERSON SUPPORTING ME

### 1 Appointment information

<b>My Name</b>	
First	Last

<b>Name of person supporting me</b>	
First	Last

<b>Appointment type</b>
<input type="checkbox"/> Family Doctor <input type="checkbox"/> Walk-in Clinic <input type="checkbox"/> Other (e.g., dentist, eye doctor, specialist, X-ray, etc.): _____ <input type="checkbox"/> Hospital Visit <input type="checkbox"/> Emergency Room Visit

<b>Things to bring with me</b>
<input type="checkbox"/> OHIP card <input type="checkbox"/> Comfort items (eg., snacks, books, games, etc.) <input type="checkbox"/> ODSP card (if going to the dentist or eye doctor) <input type="checkbox"/> Any medications I need to bring with me

### 2 Why am I going to the appointment? (Note: let the doctor know if you've already had an appointment for this reason)

**EXAMPLES:** Feeling sick, I got hurt, I need a check up, something hurts in my body, illness, injury, need more medication, medication changes or concerns, stress with family or friends, need forms filled out, etc.

### 3 Have any of these been bothering me in the last week (or longer)?

Health Concern:	Is there a problem?	What is the issue?	Is tracking sheet(s) attached?
Pain	<input type="checkbox"/>		<input type="checkbox"/>
Eating	<input type="checkbox"/>		<input type="checkbox"/>
Bathroom or toileting	<input type="checkbox"/>		<input type="checkbox"/>

# Caregivers and staff

## Barriers

- ▶ Awareness
- ▶ Training
- ▶ Mandates
- ▶ .....



# The DDPCP aims to further

- ▶ Educate
- ▶ Engage
- ▶ Enhance
- ▶ Evaluate

# Conclusion

- ▶ **Evidence** does not change practice, **people** change practice
- ▶ **Active dissemination and implementation** strategies are needed to change behaviours of primary care providers, caregivers, & patients
- ▶ **DDPCP collaborates** with stakeholders, across sectors and disciplines, to increase the uptake of evidence-based guidelines and tools, to
- ▶ **Improve the health outcomes** and health services use for adults with intellectual and developmental disabilities in Ontario

Contact us

[ddprimarycare.surreyplace.ca](http://ddprimarycare.surreyplace.ca)

[ddpcp@surreyplace.ca](mailto:ddpcp@surreyplace.ca)

[Heidi.Diepstra@surreyplace.ca](mailto:Heidi.Diepstra@surreyplace.ca)



@SurreyPlaceON

**SURREY**  **PLACE**

The logo for Surrey Place, featuring a stylized green and yellow globe with white dots, representing a globe or a cluster of people.